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# Development of a balance, safe mobility and falls management programme for people with multiple sclerosis

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1 **Development of a balance, safe mobility and falls management programme**  
2 **for people with Multiple Sclerosis**

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# 1    **Development of a balance, safe mobility and falls management programme for** 2    **people with Multiple Sclerosis**

## 3    **Abstract**

### 4    **Purpose**

5    To utilise stakeholder input to inform the structure, format and approach of a multiple  
6    sclerosis balance, safe mobility and falls management programme

### 7    **Materials and Methods**

8    Using a three-round nominal group technique, participants individually rated their  
9    agreement with 20 trigger statements, followed by a facilitated group discussion and re-  
10   rating. Three mixed groups included service users (n=15) and providers (n=19).  
11   Quantitative analysis determined agreement, whilst qualitative responses were analysed  
12   thematically.

### 13   **Results**

14   Median scores for each of the 20 trigger statements did not change significantly over  
15   sequential rounds, however deviations around the medians indicated more agreement  
16   amongst participants over time.

17   Key recommendations were:

18   *Aims and approach:* The programme should be tailored to the needs of people with MS.  
19   Falls and participation-based outcomes are equally important.

20   *Structure and format:* The programme should balance expected burden and anticipated  
21   benefit, moving away from models requiring weekly attendance and promoting and  
22   supporting self-efficacy.

1 *Optimising engagement:* Support to maintain engagement and intensity of practice over  
2 the long term is essential.

3 *Sustainability:* Adequate funding is necessary. Staff should have multiple sclerosis  
4 specific knowledge and experience.

## 5 **Conclusions**

6 Participants collaboratively identified critical components of a multiple sclerosis balance,  
7 safe mobility and falls management programme. They also highlighted the importance of  
8 a collaborative, user-centred, multiple sclerosis-specific approach.

9 **206 words**

## 10 **Keywords:**

11 Self-management, Multiple Sclerosis, Accidental Falls, Balance, Rehabilitation, Nominal  
12 Group Technique

13

14

## 1     **Introduction**

2     Multiple Sclerosis (MS) is a chronic, degenerative neurological condition characterised  
3     by variable motor, sensory, visual and cognitive symptoms [1]. People with MS  
4     frequently experience problems with balance and mobility, and often report falls [2].  
5     These may lead to injury, activity curtailment and further deterioration in mobility levels  
6     [3,4], with a consequent impact on quality of life [5].

7     The current evidence-base to guide the development of MS falls prevention programmes  
8     is limited, although reviews suggest that programmes of gait, balance and functional  
9     training alongside safe mobility education have potential [6]. In line with studies in older  
10    people [7], evidence indicates that exercise dose and duration, and long-term adoption of  
11    safe-mobility strategies are important in achieving a positive outcome [6,8]. To succeed,  
12    it is recognised that people usually require support to develop the skills and confidence  
13    to self-manage their mobility and falls-risk effectively [9]; with studies suggesting that this  
14    support may be key to promoting uptake and adherence with programmes of this type  
15    [10,11].

16    Defining programme content is only one aspect of developing an intervention [12].  
17    Optimising programme utility is also important as adherence to rehabilitation packages  
18    can be poor [13,14], particularly in interventions which include preventative and  
19    educational components [15]. Experience in older people's falls prevention services  
20    suggests a range of factors are likely to impact on the eventual programme utility [16,17].  
21    Alongside an evaluation of the evidence base to inform content, stakeholder input is  
22    therefore critical to ensure the programme structure and format is feasible and  
23    acceptable to service users and providers.

## 24    ***Aims and objectives***

25    This study aimed to explore service users' and providers' views of the most suitable  
26    methods and formats of delivery for a balance, safe mobility and falls guided self-  
27    management programme for people with MS. The specific study objectives were to  
28    determine:

- 1           1. Programme aims, outcomes and approach
- 2           2. Programme structure, format and delivery methods
- 3           3. Factors affecting participant engagement with and adherence to the
- 4                 programme, both over the short-term and longer term
- 5           4. Factors affecting sustainability and integration of the programme within
- 6                 existing service provision

7

## 8   **Materials and Methods**

9   The study used a consensus development approach, employing a nominal group  
10 technique (NGT) [18]. This approach uses expert input to explore opinions and evaluate  
11 consensus through sequential rating, discussion and debate focussed around a series of  
12 trigger statements [19]. Individual and group activities are employed within a structured  
13 and facilitated process [20], aiming to stimulate discussion and sharing of ideas whilst  
14 ensuring that all participants have equal representation [21]. The process generates both  
15 quantitative and qualitative data: Quantitative analysis allows the ranking to be presented  
16 back to the group after each round, so that they can consider their own response in the  
17 context of the group consensus. Qualitative analysis provides a more comprehensive  
18 explanatory account of the rationale underpinning participant responses [22]. These  
19 analyses are a central tenet of consensus development techniques [23].

20

## 21   **Participants**

22   Purposive sampling was used to recruit a range of people with relevant expertise,  
23   including:

- 24         • People with MS who had/ had not fallen, and who were representative of the
- 25                 range of disease types and severity
- 26         • Rehabilitation professionals from varied backgrounds and service delivery
- 27                 settings
- 28         • Service commissioners, and

- 1       • Other individuals likely to be able to contribute expertise to the group (e.g. staff  
2       running falls groups for older people).

3 Participants were excluded if they did not have the capacity to give informed consent, or  
4 had severe communication difficulties preventing full participation in the nominal group  
5 sessions. Participants were recruited via advertisement and targeted visits to local  
6 networks, support groups and existing services. Permission for the study to proceed was  
7 obtained following ethical review by the South West (2) NHS Research Ethics Committee  
8 (Ref 13/SW/0309).

### 9 ***Formation of nominal groups and sample size***

10 Three nominal group panels were convened covering the main geographical localities of  
11 the study area (South West peninsula, United Kingdom). With a recommended group  
12 size of no more than 12 members per nominal group [24], this represented a total  
13 maximum sample size of 36 individuals.

### 14 ***Nominal Group Plan***

15 The stages of the nominal group process are summarised in figure 1. Prior to the  
16 meeting all participants received briefing and training; service providers received a  
17 mailed briefing paper, whilst MS service users were invited to attend a half-day training  
18 session led by the project team alongside a facilitator from the South West Peninsula  
19 Collaboration for Leadership in Applied Health Research and Care (PenCLAHRC) Public  
20 Involvement Group.

21 The group meetings were convened in accessible local community venues; and  
22 scheduled to last a maximum of five hours (including two breaks). Each session was co-  
23 facilitated by the project researchers (HG or JF) and a research team member with  
24 extensive training and experience in running consensus groups (RE). A third team  
25 member acted as an observer, to make a non-attributable record of the process and  
26 dynamics relating to the consensus discussions, which were used as a reference source  
27 during analysis.

1 *Insert figure 1 about here*

## 2 **Data analyses**

### 3 *Quantitative data analyses*

#### 4 *1. Statement rating scores*

5 Participants were asked to rate their response to each trigger statement (Figure 1) using  
6 a 9-point Likert scale (1=strong disagreement, 5=neutral, 9=strong agreement), with  
7 summary data of the responses presented to participants at each stage. On completion  
8 of the process, the median, inter-quartile range (IQR) and absolute range for each  
9 statement for each round was calculated.

#### 10 *2. Evaluation of the level of agreement between participants*

11 For each statement, agreement between the participants was evaluated at each stage by  
12 determining the mean deviation from the median (MDM) [25,26], calculated as:

$$13 \quad \frac{\text{Sum of individual deviations from the median}}{\text{Number of participants}}$$

14 The MDM was subsequently categorised to indicate strong, moderate or weak  
15 agreement by calculating the round one absolute MDM, which is then split into thirds  
16 [25,26].

#### 17 *3. Evaluation of rating scores*

18 Wilcoxon signed-rank tests were undertaken to evaluate change in the rating scores and  
19 the MDM for each statement between the rounds. Mann-Whitney U tests were  
20 undertaken to investigate differences between the service user and provider scores at  
21 each round. Bonferroni corrections for multiple analyses were undertaken throughout,  
22 resulting in an adjusted *p* value of 0.017 [27].

### 23 *Qualitative data analysis*

24 The NGT process generated two types of qualitative data: written responses to the  
25 trigger statement questionnaires and audio transcriptions from the NGT meetings.

26 Written responses were recorded on an excel spreadsheet at each stage, whilst group



1 meetings were audio recorded and fully transcribed. The two sources were checked for  
2 similarity and subsequently combined for analytical purposes in NVIVO [28,29]. Thematic  
3 analysis was undertaken using a pragmatic process of data immersion, coding and  
4 generation of categories which were developed with reference to the original aims of the  
5 study [30]. To assure that the codes were derived reliably, initial coding of the transcript  
6 from one nominal group meeting was undertaken by two independent members of the  
7 research team (HG, JF). To ensure the robustness of decisions made, as analysis  
8 continued, the inductive development of categories was discussed regularly by the team.

### 9 ***Development of position statement***

10 On completion of the data analyses, results were synthesised into a position statement  
11 summarising the key recommendations. This statement was circulated to all participants,  
12 13 of whom provided feedback (7 service users, 6 providers), which was incorporated  
13 into the final position statement. This document is available from the corresponding  
14 author on request.

## 15 **Results**

### 16 ***Participant characteristics***

17 Thirty-nine people volunteered for the study, however five were unable to attend the  
18 nominal group meetings, leaving a total of 34 participants (Figure 2). Of these, 15 were  
19 service users and 19 service providers (Table 1).

20 *Insert figure 2 and table 1 about here*

### 21 ***Quantitative analyses***

#### 22 ***Statement rating scores***

23 A summary of the results of the rating analyses for all participants is shown in Table 2.

24 Overall, there was minimal change in the median and IQR for any of the individual

1 statements, with no significant difference in the scores between rounds one and three  
2 ( $p>0.05$ ).

3 *Insert table 2 about here*

#### 4 *Analysis of agreement*

5 There was a significant difference in the MDM between each of the rounds, with  
6 decreasing MDM values indicating an increase in the level of agreement between  
7 participants with each round of discussion and re-rating. According to the Vella [26]  
8 method of classification, final rating agreement was rated as low for 16 statements and  
9 moderate for four statements; none of the statements were ranked as having high  
10 agreement.

#### 11 *Scoring between participants*

12 On average, the MS service users scored more highly (indicating a higher level of  
13 agreement with each statement) than the service providers, however, the differences in  
14 the final scores between the two types of participant were only statistically significant for  
15 two statements (statements 10 and 14). These related to the provision of exercise  
16 supervision and service funding respectively.

#### 17 **Qualitative analysis**

18 The findings of the qualitative analyses are grouped according to the main aims of the  
19 study and presented below, with the collated round 3 ratings scores presented alongside  
20 where appropriate. Quotations are referenced by participant number with an  
21 accompanying brief participant description to add context.

##### 22 *1. Programme aims, outcome and approach*

23 There was moderate agreement that the balance, safe mobility and falls programme  
24 should include both exercise and educational content (educational elements, final  
25 median 9, MDM 0.58; exercise elements final median 8, MDM 0.52). Participants  
26 recognised that these elements are included within the majority of existing falls services,

1 but considered that the content of a falls programme for people with MS should be  
2 different.

3 People with MS have very separate needs to 'average' users of falls services (e.g. over  
4 65's) *Falls prevention specialist physiotherapist, female (SP17)*

5 Service users highlighted limited availability of falls rehabilitation services for people with  
6 MS; even amongst those who described themselves as falling regularly. This experience  
7 was validated by the service providers, who commented that few people with MS were  
8 referred to existing falls programmes. There was a belief amongst service users that  
9 these generic (typically oriented towards older people) falls services did not meet their  
10 needs.

11 By the nature of it it will tend to be older people who go [to the falls service], and then if  
12 you're someone young with say progressive MS, you may be grieving for your former self  
13 anyway without having it thrust in your face that you are falling around like your Gran.  
14 *Female, 35 years old, relapsing remitting MS, previously referred to a falls service (did*  
15 *not attend) (SU16)*

16 The group rating scores indicated agreement that reducing falls should be a primary goal  
17 of the programme (final median 8, MDM 0.91). However, the importance of functional  
18 outcomes was emphasised (final median 7, MDM 1.06), with discussions highlighting the  
19 need to decrease falls without compromising levels of activities and participation.

20 If I was commissioning a group and everyone in the group had fallen three times before  
21 they joined and no times afterwards, but they had spent six weeks being miserable, or  
22 living lesser lives because they were taking less risks as a result, then that's not an  
23 outcome I would be particularly interested in. *Service commissioner (long term*  
24 *conditions), female (SP14)*

25 Developing self-management strategies was suggested to be an important aim for the  
26 programme. This included increasing knowledge about falls risk factors and supporting  
27 the development of coping strategies.

28 Giving people the tools to take control of their condition is really important. *Community*  
29 *physiotherapist, female (SP16)*

## 30 2. Programme structure and format

31 The score for the statement relating to use of group sessions in the programme was  
32 neutral (final median 6, MDM 1.12), with discussions in all three NGT meetings

1 identifying that a variety of formats could be effective. However, groups were felt to  
2 provide important positive benefits.

3 With regard to exercise groups that I've been a participant in, somehow there is some  
4 kind of, um, 'group energy' that comes about. I don't know if its competition or what it is,  
5 but there definitely is something there in the group. *Male, primary progressive MS (30+*  
6 *years) (SU15)*

7 However, there was recognition that a variety of personal factors may affect peoples'  
8 preference for group or individual activities.

9 I've got patients who have MS who will not go to groups, so it's making sure that there is  
10 something available for them..... *Neurology specialist physiotherapist, female (SP8)*

11 The frequency and duration of attended sessions were identified as potential issues, with  
12 participants highlighting that MS specific issues may significantly impact on participants'  
13 ability to achieve this.

14 It's not a question of motivation necessarily, it's a question of falling ill in between times or  
15 having hospital appointments that clash or just life -I don't think I could guarantee I'd be  
16 there every week at the same time for 20 weeks. *Female, secondary progressive MS*  
17 *(20+ years) (SU10)*

18 The feasibility and choice of setting for programme elements which might be held away  
19 from the participant's home was the subject of significant discussion. The logistical  
20 challenges of rurality were recognised, however participants felt that living in a remote  
21 location made access 'difficult' rather than 'impossible' (final group median 5, MDM  
22 1.30).

23 I suppose there's a variation between some people who will overcome all sorts of barriers  
24 to get there because they really want to come, and other people who down the road is too  
25 far *MS specialist nurse, female (SP7)*

26 The need to optimise convenience for participants was emphasised, with discussions  
27 highlighting the impact of travelling distance and time on MS specific issues such as  
28 fatigue. It was suggested that the number of essential face-to-face sessions in a  
29 programme was an important consideration.

30 I think if they're coming for a one-off, that's something that you can work around, but if  
31 you're coming week after week I wonder how much convenience and accessibility has a  
32 part to play. *Neurology/ general community physiotherapist, female (SP12)*

1 Despite the positive perceptions of group-based activities, applying learning and  
2 undertaking exercise at home was deemed essential to the programme's success,  
3 regardless of whether group sessions were included or not. Participants highlighted the  
4 challenges associated with self-management, and the need for strategies to be included  
5 to provide support and maintain motivation for this aspect of a programme.

6 I don't, I don't, I need to be in a group for things to happen properly. I've tried this lots of  
7 times to do things properly; I'm thinking this all needs a group. Singly I don't know if I  
8 would bother to do it. *Female, secondary progressive MS (16+ years), falls regularly*  
9 *(SU10)....*

10 .... I agree: In our [older people's] falls and balance group I always say, "now who's done  
11 the exercises since last week"? And I'll get about two hands out of eight.... *Falls service*  
12 *lead, female (SP20). Discussion excerpt*

### 13 3. Optimising engagement

14 The importance of sustaining a high level of engagement over a long period was widely  
15 recognised. Personal choice was perceived to be an important factor affecting  
16 engagement and adherence, however there was widespread agreement that  
17 professional input was essential to guide and support activities.

18 I would like my goals to be taken into consideration, but equally I need help to identify the  
19 exercises that can help me achieve those goals. It's all very well me saying that my  
20 balance sucks, but I need someone to say why my balance sucks and what they can do  
21 about it. *Female, relapsing remitting MS (<5 years), falls regularly (SU16)*

22 The need for exercises to be challenging in order to be effective was recognised by both  
23 professional group members and people with MS; however, striking a balance between  
24 challenge and achievability was highlighted as a key consideration.

25 It's getting the balance between, it's got to be challenging enough to actually progress  
26 balance, if it's easy you're not going to progress the balance at all; but at the other end if  
27 they're too difficult then people give up. You've got to progress, to start something easy  
28 and then move up. *Therapy assistant, female (SP10)*

29 It was identified that programme participants were likely to need significant  
30 encouragement and support to develop the confidence to undertake highly challenging  
31 balance exercise. Lack of confidence was recognised as a barrier to exercise alongside  
32 physical ability.

1 I think sometimes you have to push yourself to know what you can and can't do physically  
2 and mentally. *Male, secondary progressive MS (11-15 years) (SU20).....*

3 ...You might try those [difficult] exercises with a little 'prodding'... *Female, secondary*  
4 *progressive MS (<5 years) (SU18).....*

5 ...I think I might need a little bit more than 'prodding'... *Female, secondary progressive*  
6 *MS (11-15 years) (SU17). Discussion excerpt*

7 The need for frequency of practice of both behavioural and exercise elements of a  
8 balance, safe mobility and falls programme was recognised. It was suggested that  
9 supporting participants to identify their own needs and preferences would be beneficial,  
10 whilst also being more in keeping with an ethos of self-management.

11 Daily, in the form of exercises at home-if you want me to do two hours of exercise you  
12 can forget it; I have better things to do even though it may help me self-manage my  
13 condition. *Female, relapsing remitting MS (<5 years), falls regularly (SU16)*

14 Panel members recognised the challenge of maintaining engagement in a programme  
15 over a long period. It was proposed that ongoing engagement is likely to be dependent  
16 upon the success of integrating the exercise and educational aspects of a programme  
17 into the participant's daily lifestyle.

18 I think it might be helpful if the programme incorporated [functional activities] rather than  
19 saying "try and do this certain programme at home for however long". Saying "actually, in  
20 the tasks you're undertaking at home every day, if you did it this way then actually you  
21 would be incorporating or helping to progress what you learnt". *General community*  
22 *physiotherapist, female (SP12)*

23 There was a recommendation that a balance, safe mobility and falls programme needed  
24 to include strategies to aid adherence and to help people get back on track after relapses  
25 or other issues.

26 I think as well as along with the motivation... it's important to help people deal with the  
27 fact that some days and weeks they're just not going to be able to exercise, and  
28 sometimes they will have setbacks and not just giving up, but being able to come back  
29 and keep coming back. *MS specialist nurse, female (SP7)*

#### 30 4. Programme sustainability

31 Long-term sustainability was considered critical. Participants identified the importance of  
32 "doing it properly or not at all" to optimise effectiveness and satisfaction for both staff and  
33 service users. Service providers consistently highlighted the difficulties associated with

1 current levels of service provision and funding, suggesting that meeting the demands of  
2 a new MS falls service within existing resources would be challenging

3 It needs to have its own resources because you get fed up trying to run everything on a  
4 shoestring and rushing in and doing a group and then rushing off again to the next thing.  
5 *Neurology specialist physiotherapist, female (SP8)*

6 The leadership and facilitation role was seen as central to the long-term success of a  
7 programme. A large number of skills and attributes were identified as being necessary  
8 (figure 3), but, it was viewed as essential for the programme leader to have MS specific  
9 knowledge, regardless of professional discipline, or qualification.

10 *Insert figure 3 about here*

11 It's not just that somebody is highly qualified that's important, it's that somebody has  
12 experience of and understands MS. I have had Physio from a non-neuro Physio and ...it  
13 is not as effective or as enjoyable as having someone specialist looking at the way you're  
14 doing your exercises and responding to what you're doing. *Female, relapsing remitting*  
15 *MS (6-10 years), does not fall (SU4)*

16 In discussion, the participants explored the importance of leadership approach and the  
17 rapport between programme participants and the programme leader.

18 I think the relationship between the therapist, the enabler, whatever we want to call this  
19 wonderful being who is leading this group, and the people of the programme is utterly  
20 paramount. Because unless that sense of trust, respect, friendliness is there, the  
21 opportunity isn't going to be exploited to the full. *Female, relapsing remitting MS (<5*  
22 *years) (SU16)*

23 Supervision and feedback was seen as essential to encourage and maintain  
24 engagement with the programme. However, members identified that a collaborative,  
25 partnership approach was essential.

26 It's a partnership, because the therapist needs to know..., then the people with MS also  
27 need to have an idea ...so that they can tell the therapist when they're reaching that  
28 point. So, it's always a two-way conversation. *General community physiotherapist, female*  
29 *(SP19)*

## 30 **Discussion**

31 This study utilised a novel application of the nominal group technique to inform the  
32 structure, content and delivery method of a balance, safe mobility and falls guided self-

1 management programme for people with MS. The quantitative data indicated the  
2 strength of opinion and level of agreement relating to each of the statements, whilst the  
3 qualitative data added depth and detail. Both sources of data were valuable to inform the  
4 development of the final position statement and to identify ongoing uncertainties.

#### 5 ***Programme aims and approach***

6 The results indicate that reducing falls whilst maintaining or improving activity and  
7 participation in daily life should be primary aims of the programme. Work by Laybourne  
8 [31] previously highlighted the risk to activity and independence outcomes that a pure  
9 focus on falls reduction may present [32]. The findings of this study suggest that tailoring  
10 the programme to optimise balance and 'safe mobility' (as against 'falls prevention'), and  
11 integrating the content into the participants' daily lives from the outset may provide  
12 opportunities to improve engagement and adherence to the programme.

13 There was a recurring theme that individual responsibility and the successful utilisation of  
14 self-management approaches would impact on the success of all elements of the  
15 programme. However, the importance of providing targeted support and advice to  
16 progress activities and maintain motivation was recognised. As with other studies [33],  
17 there was widespread acknowledgement that input from programme leaders was crucial.  
18 The nature of the relationship between the programme leader and participant was felt to  
19 be critical to achieving the balance between 'expert' and 'participant'. The overall  
20 recommendation is for an approach which develops a "collaborative partnership". Other  
21 studies suggest that this approach can be challenging for the staff providing the  
22 programme, requiring a change of emphasis and approach [10].

#### 24 ***Programme structure and format***

25 The findings of this study are broadly in agreement with others [34], suggesting positive  
26 perceptions of group-based activities amongst many people with MS. However, studies  
27 also emphasise that there are challenges associated with solely group-based



1 rehabilitation programmes [35–37]. The NGT results align with this: Panel group  
2 members viewed frequent attendance as especially challenging, particularly in long-  
3 duration programmes and in rural areas. A programme with a relatively low number of  
4 group sessions, or where sessions are spread over time could be more attractive and  
5 feasible to people than a programme requiring attendance once or twice a week for a  
6 longer period. However, evaluation is essential to ensure that a balance is struck  
7 between optimising feasibility and maintaining effectiveness; this has yet to be explored  
8 empirically.

### 9 ***Optimising engagement***

10 Maintaining engagement in falls programmes has been cited as a key factor influencing  
11 outcome, both in the short and long-term [38]. Alongside more general challenges,  
12 people with MS may experience a range of condition-specific issues negatively impacting  
13 on longer-term adoption of exercise interventions [39]. In this NGT study, the need to  
14 structure activities so that they became habitual and integrated into daily life was  
15 emphasised, as was the importance of supporting participants to get back on track after  
16 interruptions (for example due to health issues). Different behavioural approaches  
17 utilising a range of strategies to improve or maintain engagement with general physical  
18 activity programmes have been evaluated in people with MS [40–42]. In general,  
19 participant satisfaction with the value and utility of these interventions has been high  
20 [43,44], although physical activity outcomes to date are more mixed [41,43,45–47].

### 21 ***Programme sustainability***

22 These results emphasise the importance of developing an MS specific balance, safe  
23 mobility and falls guided self-management programme which is appropriately funded and  
24 yet sustainable within current models of service delivery. The qualitative findings  
25 highlight the lack of utilisation of existing falls services by participants in this study,  
26 despite over half of them reporting having fallen in the past year. Participants described  
27 a general ‘normalisation’ of falling and a lack of focus on falls during healthcare

1 interactions, despite recommendations that falls and balance issues should be assessed  
2 as part of the regular MS review process [48,49]. This, coupled with the perception that  
3 existing (typically older people's) falls services are not suitable to their needs, is likely to  
4 influence service use. In order to make the case for funding of MS specific falls services,  
5 research will be required to demonstrate the need for and value of any intervention,  
6 alongside the provision of evidence that referral into existing falls services is less  
7 effective. This has yet to be determined.

### 8 ***Strengths and weaknesses of this study***

9       This study aimed to determine the most appropriate format, structure and delivery  
10 methods for balance, safe mobility and falls programme for people with MS, considering  
11 issues of sustainability, feasibility and fit with existing services. We believe the use of  
12 nominal group methodology, complemented by our approach to training users and  
13 actively supporting them throughout the process, optimised their participation, although  
14 we are not aware as to whether this has been formally evaluated in other studies.  
15 Importantly it provided a robust, reproducible process which enabled discussion and  
16 exchange of ideas between service users and providers in contrast to other studies,  
17 wherein service users and providers contributed in separate sessions [50]. Analysis of  
18 the scoring between the participants did reveal small differences between the two  
19 groups, suggesting that each has different perspective to offer.

20 There are limitations to this study: Despite purposive sampling, only one service  
21 commissioner and one therapy assistant were recruited, and no representatives from the  
22 voluntary sector attended the NGT meetings. *We appreciate that attendance at an all-*  
23 *day meeting can be a challenge for many people. Use of an alternative methodology*  
24 *(such as a Delphi technique) could have reduced the time commitment required for*  
25 *participants, allowing them to make their contributions at a time and place suitable for*  
26 *them.* In the second NGT meeting there was an imbalance between service user and

1 provider representation, with only two service user participants attending the session.  
2 However, the scores and recommendations from this group were not significantly  
3 different to the other two meetings where there was a more balanced spread of service  
4 users and providers. [Given the nature of MS, it is likely that issues affecting attendance](#)  
5 [are highly likely to occur; therefore, in future studies we would recommend that](#)  
6 [researchers aim to recruit at least equal numbers of professional and service user](#)  
7 [participants to allow for such issues to arise without overly affecting group dynamics.](#)

8 Of the 15 MS service users, 10 had previously been involved in falls prevention  
9 research, suggesting they had a particularly keen interest in the topic. This recruitment  
10 bias may have limited the range of viewpoints expressed which may have impacted on  
11 the discussions and resultant recommendations. [Thus, it is important that the](#)  
12 [experiences of staff and service users involved in any interventions informed by this](#)  
13 [research are thoroughly evaluated to confirm the acceptability and utility of the](#)  
14 [recommendations.](#) Caregivers/spouses were not invited to participate in this study. Given  
15 their potential role in program adoption and adherence, their views are an important  
16 perspective, however we wished to provide service users with an opportunity to express  
17 views that they may not have felt free to do should caregivers / spouses be present.  
18 Further research to explore this would be beneficial. Although the final position statement  
19 was developed in response to the data generated in the group meetings, a less than  
20 50% response rate to the member checks could limit credibility of these  
21 recommendations. [Owing to limited time, the position statement was circulated](#)  
22 [electronically, with a single reminder email sent to encourage comments. Alternative](#)  
23 [methods of communication \(for example telephone follow up\) could have enhanced the](#)  
24 [response rate.](#) Finally, all the NGT meetings were undertaken in one geographical area  
25 of the United Kingdom. Future work to canvas a wider range of views and ideas,  
26 including a range of stakeholders from varied locations both within and out of the UK (for  
27 example through a Delphi study) could enhance transferability of these findings.

1           This study builds on previous work indicating that an MS specific programme to  
2 address balance, safe mobility and falls is required [2,6]. The findings suggest that  
3 activity and participation measures should be included as key outcomes alongside  
4 evaluation of falls rate. We have also identified potentially important elements of  
5 programme structure likely to influence the feasibility and acceptability of a programme.  
6 These include balancing expected burden and anticipated benefit for participants in the  
7 planning, delivery and format of the programme. The need for participant choice, control  
8 and independence is highlighted; however, the importance of ongoing tailored support  
9 should not be underestimated. Participants recommended that development of the  
10 programme should be done 'right or not at all', including securing appropriate funding,  
11 ensuring a fit with existing services and recognising the key role and high-level attributes  
12 required by staff providing and supporting the programme.

13 **4656 words**

14  
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21  
22

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3

4

# 1 Tables

Service providers (attendees)			
	Profession	Specialism	Number
	Therapy assistant	Rehabilitation (general)	1
	Service Commissioner	Long term conditions	1*
	Specialist Nurse	MS	2
	Occupational Therapist	Community rehabilitation (general)	1
		Neuro rehabilitation	1
		Falls Service lead	2*
	Physiotherapist	Community (general)	5
		Community (neurology)	1*, 2
		Consultant neurology	1*
		Falls specialist	1
		Private (neurology)	1
MS service users (attendees)			
	Self- reported MS Classification		
		Relapsing remitting	6
		Primary progressive	2
		Secondary progressive	5
		Other/ Unknown	2
	Gender		
		Female	11
		Male	4
	Years since diagnosis		
		0-5	2
		6-10	5
		11-15	3
		16+	5
	Mobility		
		Walking unaided	7
		Walking with stick(s)/ crutches	7
		Walking with frame/ wheelchair	1
	Falls status <sup>1</sup>		
		≥2 falls in past year	7
		1 fall in the past year	2
		No falls reported	6
	Previous involvement in fall prevention research <sup>1</sup>		
	Yes	10	
	No	5	
Previous access to a fall prevention programme <sup>1</sup>			
	Yes	1 <sup>2</sup>	
	No	14	
Non- attendees			
	Nominal Group One		
		Community physiotherapist	1
		MS service user	1
	Nominal Group Two		
		MS service users	2
	Nominal Group Three		
	Occupational therapist (falls lead)	1	

2 <sup>1</sup>: Self-report; <sup>2</sup>: 1 person had previously been referred to a falls prevention programme but chose not to attend; \* denotes  
3 service provider with managerial responsibility

4

Table1: Participant characteristics

Statement Number	Statement	Median scores (Interquartile range)				Absolute range				Mean deviation from the median (MDM)		
		R1	R2	R3		R1	R2	R3		R1	R2 <i>p</i> = 0.001 <sup>a</sup>	R3 <i>p</i> = 0.01 <sup>b</sup>
Programme outcome statements												
1	Reducing falls should be a primary goal of the programme	8 (2)	8 (2)	8 (1)		5-9	3-9	3-9		1.00	0.97	0.91**
17	Being able to see improvements in function is more important than measures of balance or falls	7 (2)	6 (2)	7 (2)		3-9	3-9	4-9		1.32	1.33	1.06
18	Daily diaries are essential to check that exercises are carried out	6 (2)	5 (2)	5 (2)		2-9	1-9	2-9		1.36	1.64	1.52
19	Programme leaders should regularly discuss progress with individual participants	8 (2)	8.5 (1)	8 (1)		5-9	5-9	5-9		0.94	0.76	0.76**
Programme structure and format statements												
2	People with MS should be given specific exercises to carry out to improve balance	8 (1)	8 (1)	8 (0)		4-9	6-9	6-9		0.85	0.62	0.52**
3	Advice to help people cope with falls should be a key part of any falls programme	9 (1)	9 (1)	9 (1)		6-9	7-9	7-9		0.47	0.50	0.58**
4	Exercise is more effective when carried out in a group	6.5 (3)	6 (2.75)	6 (2)		3-9	3-9	4-9		1.50	1.44	1.12
8	People should be able to access the falls programme without having to be referred	8 (2)	8 (2)	8 (2)		4-9	5-9	3-9		1.19	0.94	1.06
9	Any sessions outside the home should be organised in a hospital setting	2 (2)	2 (2.75)	2 (2)		1-9	1-9	1-9		1.42	1.35	1.36
10	Exercise should always be supervised	5 (3)	5 (3)	5 (3)		1-9	1-9	1-9		1.79	1.79	1.67

Statement Number	Statement	Median scores (Interquartile range)				Absolute range				Mean deviation from the median (MDM)		
		R1	R2	R3		R1	R2	R3		R1	R2 <i>p</i> = 0.001 <sup>a</sup>	R3 <i>p</i> = 0.01 <sup>b</sup>
16	Living in a remote location means that taking part in a programme away from home is impossible	5 (3)	5 (2)	5 (2)		1-8	1-9	2-9		1.56	1.41	1.30
Optimising engagement statements												
5	Exercises should be done on a daily basis	7.5 (2.75)	7 (2)	7 (2)		2-9	2-9	2-9		1.53	1.32	1.24
6	Exercising for an hour at a time is unrealistic	6.5 (3)	6 (3)	6 (2)		1-9	2-9	2-9		1.68	1.55	1.33
7	Participants should be able to choose the types of exercise in their falls programme	7 (2)	5 (2)	6 (2)		2-9	3-8	2-9		1.50	1.15	1.24
11	It is unreasonable to expect people with MS to do balance exercises that are difficult for them	4 (4)	4 (2.75)	4 (2)		1-9	1-8	1-8		1.97	1.56	1.48
20	It is unrealistic to expect people to undertake a falls programme for 3-6 months	3 (2)	3 (2)	3 (2)		1-9	1-9	1-9		1.53	1.38	1.30
Programme sustainability statements												
12	The role of the programme leader should be to push participants to their limits	5 (3)	5 (1)	6 (2)		1-8	1-7	2-8		1.55	1.38	1.12
13	Programme leaders must have formal qualifications	7.5 (3)	8 (3)	7 (3)		3-9	3-9	4-9		1.56	1.41	1.21
14	A falls programme should be provided within existing resources	5 (3)	5 (3)	5 (3)		1-9	1-9	1-9		1.88	1.82	1.70
15	It is reasonable to ask participants to pay a contribution to the cost of any attended sessions	5 (1.75)	5 (1)	5 (2)		1-8	1-8	2-8		1.00	0.91	1.00

R1: round 1; R2: round 2; R3: round 3.

Likert scoring ranges: Scores of 1-3: Disagree; Scores of 4-6: Neutral; Scores of 7-9: Agree;

MDM scoring: lower MDM indicates greater agreement  $p$ = significance using Wilcoxon signed-rank test;  $a$ : comparison between R1 and R2;  $b$ : comparison between R2 and R3; Classification (Vella et al)[26]: Low agreement:  $MDM \geq 0.93$ ; Moderate agreement:  $MDM 0.47-0.92^{**}$ ; High agreement:  $MDM \leq 0.46$

**Table 2: Nominal group rating results (all participants)**

STATEMENT	1	2	3	4	5	6	7	8	9	10
All participants median (IQR)	8 (1)	8 (0)	9 (1)	6 (2)	7 (2)	6 (2)	6 (2)	8 (2)	2 (2)	5 (3)
Service Provider Median (IQR)	7.5 (1)	8 (1)	9 (1)	6 (2)	6 (1.75)	5.5 (2)	6 (2)	9 (2)	2 (2)	4 (2.75)
MS service user Median (IQR)	8 (2)	8 (1)	9 (1)	7 (1.75)	7 (2)	6 (2)	6 (1)	8 (2)	2 (2.5)	6 (3)
<i>p</i>	0.25	0.07	0.97	0.40	0.10	0.38	0.69	0.76	0.37	0.01*

STATEMENT	11	12	13	14	15	16	17	18	19	20
All participants median (IQR)	4 (2)	6 (2)	7 (3)	5 (3)	5 (2)	5 (2)	7 (2)	5 (2)	8 (1)	3 (2)
Service Provider Median (IQR)	4 (2.5)	6 (1.75)	7.5 (2.75)	3.5 (2.75)	5 (1)	4.5 (2.75)	7 (1.75)	5 (2.5)	8 (1)	3 (1.75)
MS service user Median (IQR)	4 (3.5)	6 (2)	7 (1.5)	5 (2)	5 (2)	5 (2.5)	7 (2)	6 (2.5)	8 (1.5)	3 (2)
<i>p</i>	0.33	0.88	0.56	0.01*	0.83	0.12	0.28	0.11	0.81	0.86

IQR: inter-quartile range; \*=  $p > 0.017$  using Mann-Whitney U test;

**Table 3: Comparison of final round scoring between service providers and MS service users**



## **Figure Legends**

### **Figure 1: Nominal Group stages**

UTA: unable to attend

### **Figure 2: Participant flow chart**

### **Figure 3: Summary of leadership skills and attributes identified within the NGT meetings**



